

August 17, 2016

Developmental Disabilities Community Forum

Buttonwoods Community Center, Warwick

Meeting Minutes

State Leadership in Attendance:

- Jennifer Wood, Deputy Secretary, Executive Office of Health and Human Services
- Becky Boss, Acting Director, Department of Behavioral Healthcare, Developmental Disabilities and Hospitals
- Jane Gallivan, Acting Director, Division of Developmental Disabilities
- Mary Madden, Consent Decree Coordinator
- Tracey Cunningham, Chief Employment Specialist
- Brian Gosselin, Senior Strategy Officer, Executive Office of Health and Human Services
- Heather Mincey, Administrator, Division of Developmental Disabilities
- Sophie O'Connell, Deputy Communications Director, Executive Office of Health and Human Services
- Joe Murphy, Assistant Administrator, Office of Rehabilitation Services

I. Introductions and Updates

- Becky Boss welcomes the group and introduces Jane Gallivan.
- Jane welcomes the group and discusses her background. She explains that she will serve as Acting Director of the Division of Developmental Disabilities until the end of September, and that she hopes to continue serving the division in a consulting capacity after that period. Jane describes the significant investments that the Governor and the legislature have made recently to improve services for individuals with developmental disabilities, including wage increases for direct service workers and additional funding to support the goals of the consent decree. Jane also addresses a few of the Division's priorities, including evaluating and improving the Division's use of the Supports Intensity Scale (SIS), using data and working to create efficiencies within the Division to provide better outcomes for the people we serve, and supporting families to engage in person-centered planning.
- Mary Madden introduces herself and describes the intent of the consent decree, which is to provide opportunities for students who are transitioning out of school and for adults to experience and learn about the world of work and make an informed choice about the services and life that they want for themselves. She emphasizes that what is happening in Rhode Island to shift away from segregated services is not unique, and that across the country, states are talking about this issue. She also addresses a common misperception about the consent decree, stressing to families that nobody is going to make their loved ones go to work at a job that isn't appropriate for them. Will still start the process to ensure everyone covered under CD has a career development plan and the opportunity to think and plan. Requirement for target pops under CD.
- Mary reviews the target populations covered by the consent decree. There are two main target populations:
 - Anyone who, at the end of 2012, was in a sheltered workshop or licensed day program (e.g., any segregated setting).
 - Anyone who has left school since 2013 and has entered the adult developmental disabilities system.
- Mary reviews some key requirements of the consent decree. Everyone covered by the consent decree will be required to:
 - Have a career development plan.
 - Receive benefits counseling, which refers to sharing information with individuals and families about the impact of income on the benefits they receive, such as housing assistance and health coverage. Individuals and families will learn at what point their

income may impact their benefits, and what can be done in response. People who are employed will be required to have an official benefits plan.

- Mary describes ongoing work to create a database that includes all members of the target population covered under the consent decree. This includes a large proportion of adults receiving developmental disability services. In the fall, the Division will start notifying individuals and families if they fall into one of the target populations. Funding will be available to support enhanced services for those individuals targeted for supported employment services.
- Tracy Cunningham introduces herself and describes her role, which includes meeting with providers to evaluate their progress establishing employment programs and teams and supporting them in this work. Tracey has been meeting with providers across the state.
- Heather Mincey introduces herself as an administrator within the division.
- Brian Gosselin introduces himself and describes his role in supporting the work of the state agency team to improve services for individuals and families. Brian will be helping the Division to implement a new vision for its work moving forward. Brian also lets attendees know that they can use the index cards on their tables to submit additional questions and comments. The Division will post a list of frequently asked questions to the BHDDH website as part of its work to improve communication with individuals and families. Brian also mentions the date of the next community forum on November 9.
- Jennifer Wood introduces herself and mentions that the notes being taken at today's meeting will be posted on the BHDDH and EOHHS websites. She also lets attendees know that while we will do our best to answer their questions today, there may be some questions we need to take back with us and report back on during the next forum.

II. **Open Discussion**

- A parent describes the positive experience his daughter had working in a sheltered workshop, and how those opportunities have effectively been eliminated. He asks why this is the case, and whether the consent decree says that there should no longer be any sheltered workshops.
- Mary Madden responds that while the consent decree does not include this specific language, across the country states are phasing out the use of sheltered workshops. Many families have also advocated for the elimination of sheltered workshops.
- Jane Gallivan comments that Rhode Island is looking at many meaningful day support options for individuals and families. She also provides information about federal funding requirements. The Centers for Medicare and Medicaid Services requires services to be provided in an integrated community setting in order to receive funding. All states must be in compliance with this rule by 2019. Across the country, states are grappling with how to accomplish this. At the same time, Congress is examining the repeal of the subminimum wage.
- A parent asks whether this means that Medicaid won't pay for their child's services if she is working only with other people with disabilities.
- Jane responds that this is correct, and that the individual also has to make above subminimum wage. She describes the creation of the subminimum wage during the Depression and how it has been corrected through the years for all populations except people with developmental disabilities. This is discriminatory.
- An attendee comments that companies are going to pay individuals with developmental disabilities minimum wage when they are only paying other employees minimum wage for producing higher outcomes.
- Jane Gallivan responds that while it can be a challenge, she has seen companies do just that. She describes what happened in Maine when all sheltered workshops were closed, and where it can be hard for many people to make a living. A former sheltered workshop opened its doors to people without disabilities, and people worked side by side

for minimum wage in an integrated setting. The phasing out of sheltered workshops represents a sea change, and change can be challenging. While the legacy system is valuable to some people, many younger people entering the system for the first time don't want to work in a sheltered workshop.

- An attendee questions whether certain populations will never be able to work without someone working with them over an extended period of time. Jane responds to discuss the availability of job coaches and follow-along services.
- An attendee comments about the sense of community that they perceive is being taken away from individuals with the elimination of sheltered workshops.
- Jane offers perspective on similar discussions that occurred when institutions were being closed in Rhode Island many years ago. She acknowledges that it is not easy to integrate individuals into the larger community, but that it can be successful when everyone participates. We have to start somewhere, because we've created a system that segregates people.
- A parent comments that their son has been working in a work center for the last several years and is happy. The parent expresses concerns that the current path is going to destroy the community that has been established.
- An attendee suggests that workshops could be made more inclusive by employing people with and without disabilities and paying them minimum wage or higher.
- An attendee describes the frustration that comes from not having a place for individuals to go. The libraries and malls are overburdened with people looking to be in the community, which does not reflect the essence of the consent decree. The attendee describes their experience with customized employment and how it can work, saying that she been able to find people jobs whose parents didn't think it could be done. She emphasizes the importance of families feeling like they are involved in the process, including the development of the Career Development Plan. The process needs to be very individualized and families need a lot of choices. This will help families feel like everyone is on the same side and that things are moving in the right direction
- An attendee agrees that there are isolated jobs out there, but that they are few and far between, and asks about the plan to get employers more on board to pay minimum wage.
- Mary responds that the federal government has been clear that subminimum wage is a discriminatory practice. She describes that more than 400 people are now working in the community at various jobs that take advantage of their unique skills. When you match a person's abilities to the right job, they should be making minimum wage because they are performing a legitimate job.
- An attendee comments that those opportunities are few and far between, and that many individuals are on a waiting list for years.
- Mary offers that the State can do a better job of sharing stories of the unique jobs that people can get. She comments that the State is intentionally referring to evidence-based practices about how to approach employment, including exposing individuals to real-life experiences that help them prepare for the world of work is about. She acknowledges that this kind of change is not easy, but that it can happen, one person at a time.
- A participant asks what this means for the people who were happy being able to work in sheltered settings?
- Mary responds that regardless of the consent decree, the State believes that people should be doing meaningful things during the day. People may only work part time, and the rest of the time, they should have the opportunity to be with their friends, in the community, doing meaningful things.
- A participant asks whether the Division of Developmental Disabilities will be providing more funding for these kinds of activities. Mary responds that the State recognizes that more personalized services are more expensive, and that the additional funds being made available for populations covered by the consent decree are intended to help people build that set of experiences.

- A participant stresses the importance of providing families with the opportunity to self-direct. The participant also emphasizes employment is only a step towards community membership. Equally important is the true integration and engagement of children in all types of experiences. There should be opportunities for self-direction in every area.
- [Inaudible comment]
- A participant comments that thanks to the closing of the institutions, people have a higher quality of life. They describe their own experience with a daughter who is very medically frail and who may never find employment, as much as her parents may want her out in the community.
- A participant asks Tracey Cunningham which providers she has been speaking with. Tracey responds that she has been working with any organization receiving funding from the Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH) or the Office of Rehabilitation Services. She has been having conversations with providers about their progress converting from sheltered work to day programs and setting up stepping stones to employment (e.g., by exposing individuals to new activities). She has also set up conversations with multiple agencies around self-determination projects and trainings. We will post a list of trainings to the BHDDH website. Tracey also mentions that she will be at the upcoming self-advocacy conference. In the future, we intend to share some stories about customized jobs.
- A participant asks if the State can provide examples of specific activities that could be done in a day center now before someone is ready to be employed, rather than traditional activities such as going to the library.
- Tracey says that we are encouraging programs to examine what people want to do (e.g. crocheting, knitting, art, etc.) and to develop opportunities based on interest. This could include integration with community colleges, senior centers, and similar places. For example, in addition to going to the movies and bowling, individuals should be exposed to new environments, where they can talk about what they've seen and the types of jobs available in those environments. An example could be visiting a senior center, observing people serving lunch, and exploring whether that's something someone might like to do.
- A participant comments about the insufficient staff at many centers, and that as a result people are not receiving individualized programs.
- A participant asks about the additional funding available to support developmental disability services and when this funding will be made available.
- Jennifer Wood clarifies that Governor Raimondo requested, and the General Assembly approved, over \$11 million in increased funding for developmental disability services this year. Five million of that funding will support wage increases for direct service providers, with the balance allocated for supported employment and other integrated, community-based services for the federal consent decree target population. The funds represent a significant investment and are targeted and performance based.
- An attendee asks whether the funds are awarded to individuals. Jennifer Wood explains that they can be accessed through self-directed or agency programming. In order to receive funds, it has to be demonstrated that an individual is engaging in specific activities incentivized by the funds, such as receiving more integrated services. Funds are not only awarded if an individual receives a job. Rather, they are also awarded to support steps along the path to employment.
- An attendee asks for an update on sharing living arrangements. Jennifer Wood describes federal law, which requires anyone receiving services from the State to receive those services in the least restrictive environment appropriate to his or her needs. Therefore, the State has a policy that supports placement under this requirement. For each individual, we start by asking what the most home- or family-like setting would be that is appropriate for that person. While group homes are appropriate for some individuals, they are considered a more restrictive environment

and may not be the most appropriate setting for others. People have different needs, so there will continue to be an array of different kinds of living arrangements available.

- An attendee asks where the State is in the transition process, and whether people with disabilities and their families will be included in the process of choosing the new leaders for the Department. Jane Gallivan responds that there needs to be a tremendous amount of family input in this process. The Department has submitted a transition plan to the federal government that needs to be continuously updated, and that the Department is required to provide public notice if there's a change. That process represents an opportunity to provide input into the plan. Jane also invites attendees to provide input on the qualities they would like to see in a leader for the Division of Developmental Disabilities.
- An attendee asks whether that person will be responsible for all of BHDDH, or just on developmental disabilities. Jennifer Wood responds that the Department will be searching for permanent leadership for two different positions – the BHDDH Director and the Division of Developmental Disabilities Administrator.
- An attendee asks about the timeline for hiring. Jennifer responds that we are looking to recruit a permanent Administrator for the Division of Developmental Disabilities this fall. We have not yet set a timeline to recruit a permanent BHDDH Director. Acting Director Becky Boss has agreed to serve for an extended period of time at the request of the governor as we develop a plan for that transition.
- A participant describes their experience with two daughters who have major medical issues and may have trouble finding employment. They have been trying to get a transition plan in place for their younger daughter for years. While acknowledging that emergency situations must take precedence, the participant questions why they cannot get a concrete plan in place.
- A participant asks whether there is someone parents can talk to, as that can be a very overwhelming process. The participant asks whether there is expertise within the Division to develop resources for residential and other services. Jane responds that this has been identified as a clear need.
- An attendee asks whether specific criteria have been developed to evaluate progress. Jane responds that this is part of Brian Gosselin's new role. She also explains that the consent decree includes specific criteria that may be used to examine progress across the entire developmental disabilities system.
- Mary Madden explains that the primary focus of the consent decree is on employment. We are also measuring whether people are spending more time in community doing other things; whether people have a plan that starts to move them to employment; and how transitions are going for young people moving from high school into the adult world. The consent decree covers multiple state agencies, because there is an expectation that we create a seamless transition that prepares students for work starting at age 14, and that they enter adult services with experience.
- Brian Gosselin explains that part of his role is to help determine the vision for the developmental disabilities system and whether we've made progress towards that vision. He invites attendees to share feedback on that process. Brian also offers perspective on the limited data capacity of many state agencies and the expense associated with case management systems. We have been working hard with the Sherlock Center to collect data related to the consent decree, which represents the first time in many years that we are gathering this type of information across the system.
- A participant asks about current surveys underway. State officials explain that the Sherlock Center has been conducting surveys on day and employment services for over 3000 people. Agencies submit data for this survey.
- A participant asks about the relationship between the SIS interview and funding tier level. State officials discuss the additional questions included in all new SIS surveys. While there may still be a need to ask for exceptions to an assigned tier, this should be a stronger tool and reduce that need.

- A participant asks where the SIS get evaluated. State officials explain that SIS tiers were developed by company that looks at the assessed level of support need and associated costs. There is an algorithm behind the score and associated funding level. The use of this tool is standard practice across the country.
- A participant asks about the role the SIS will continue to play in career development, sharing her experience with her daughter, who loves science and math but who got a retail job that did not go well. She expresses disappointment that the Job Club opportunity no longer exists at the Groden Center.
- Tracey Cunningham responds that agencies are working collaboratively to examine the contributions and needs of people being referred. Employment teams will help teach individuals the skills sets they need to prepare for work.
- Joe Murphy explains that based on his understanding, the Groden Center Job Club did not lose funding, but was ended due to insufficient capacity.
- A participant suggests that a sound system be made available for future meetings. Another suggests that more advance notice and sharing an agenda ahead of time would be helpful. Regional meetings could also be considered.
- Jane Gallivan announces that the next meeting will be on November 9, and that more information will be shared when available. She also asks the group for feedback on preferred communication strategies. Email appears to be the preferred method of communication, while posting on the website is also helpful.
- A participant comments that not everyone has email or internet in their homes and that it would be helpful to have meetings at different times. She suggests that people who are really stressed and can't attend in person be provided with an opportunity to ask questions and provide feedback as well.
- Another participant suggests that it would be helpful to have a dedicated button on the website to find information for parents.
- A participant observes that it may be helpful to see how providers are sharing information with families and individuals.
- Another participant requested a handout with the names of key staff members and their position titles.
- A participant comments that some self-directed participants are starting a social group. This is something they want to do, even though it may be considered a segregated community.
- A participant comments that clear contacts are needed who can address specific issues.
- Jane Gallivan closes the meeting by thanking participants for attending and inviting them to submit questions that did not get answered today using the index cards available on each table.

[Meeting ends.]